



Donate Life

Missouri Organ and Tissue Donation 2011 Annual Report



Missouri



Governor's Organ Donation Advisory Committee

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Organ and Tissue Donor Program MISSION

Close the gap between the need and availability of organs and tissues through informed citizens and an efficient, confidential registry of potential donors.



Peter Nicastro

From the CHAIRPERSON

It is my pleasure to serve as the chairperson of the Organ Donation Advisory Committee. The committee brings together major groups interested in promoting organ, tissue and eye donation to efficiently serve the needs of people on the donor registry, donor families, organ and tissue recipients and the generous contributors who make our work possible. As proponents of donation, we want everyone to be a registered prospective donor, and we respect the decision every Missourian makes about becoming a donor.

The committee is very interested in improving the work we do. To that end, we collaborated this past year with the Harry S Truman School of Public Affairs at the University of Missouri-Columbia. A team of graduate students spent the spring semester reviewing the program. They interviewed committee members and stakeholders, examined our data and compared it to the efforts and results of other states across the country, and tested our processes against best practices. I am happy to report that Missouri's program was generally found to be excellent. Nonetheless, there are areas for improvement, including outreach to minority residents. Meanwhile, committee members and stakeholders engaged in a parallel process to review our work from our own individual perspectives. In the coming year, we will work to integrate the suggestions from the student team with our existing strategy to improve our processes and services.

Donations to Missouri's Organ and Tissue Donor Program have fallen to a point that will put the program at risk in a few short years. When the renewal period for license plates was lengthened from one year to two, revenue fell nearly by half. Applicants who gave to the fund annually at the license office were in the office half as often. The \$1 donation amount is all that can be collected from individuals at the local license offices and has not changed since the inception of the program.

This year the committee and our partners supported a bill in the Missouri General Assembly that created an income tax check-off to benefit the Organ Donor Program Fund. Partners and friends educated legislators and spearheaded a grassroots advocacy campaign for the legislation. Gov. Jay Nixon signed the bill into law. The new check-off will appear on the 2011 state income tax form and will allow every taxpaying Missourian to donate every year. Please consider a contribution at tax time so that we can continue the donor registry and provide education about organ and tissue donation.

Kindest regards,

Peter Nicastro, Chairperson, Governor's Organ and Tissue Donation Committee



Margaret Donnelly

From the DIRECTOR

Organ and tissue donation saves the lives of thousands of people across the country every year. For many more thousands, organ and tissue donation helps improve the quality of their life.

Several years ago, Kansas City resident Chris Meyer was losing more and more of his eyesight every day due to a degenerative eye disease. He was also losing the ability to fly-fish – one of his greatest passions in life. Cornea transplants helped save Chris' ability to work, to drive ... and to fish. You can read more about Chris on page 8.

When you sign up to become an organ, eye and tissue donor, you won't know the exact impact you might have on a person's life. But you can be sure the impact you could make will be great. Whether your donation saves a life through a heart, lung or kidney transplant or helps improve a person's quality of life through a cornea or tissue transplant, you will have made a significant, life-changing difference in someone's life.

I am pleased to present this year's annual report from the Governor's Organ Donation Advisory Committee. The report reflects the efforts of hundreds of people who work together to promote organ and tissue donation and the registry. They understand the impact organ and tissue donation can have on a person's life. Through their dedication, more Missourians are making a difference by making the decision to become a donor.

Sincerely,

Margaret Donnelly, Director, Missouri Department of Health and Senior Services

2011 ADVISORY COMMITTEE

The Governor's Organ Donation Advisory Committee (GODAC) is a 10-member group that develops organ donor awareness programs to educate the public about the importance of organ donation. The group consists of four representatives from organ procurement agencies, four organ recipients, organ donors or family members of organ donors, one health care representative and one representative from the Missouri Department of Health and Senior Services. Five new members were appointed to the committee in 2011.



PHIL DUNCAN

Phil Duncan was appointed to the committee on March 10, 2011 as an organ recipient. Duncan served 35 years as a lineman for Kansas City Power and Light, is retired from the Missouri Army National Guard (25 years), and served two terms as mayor of Belton. He is involved in numerous civic organizations.

Duncan participates in volunteer and training opportunities at Midwest Transplant Network and Gift of Life, and has appeared in many parades to promote organ donation. For the past four years, he has devoted his time to educating high school students in Cass County about organ donor awareness. He has received a Medal of Honor award from the Department of Health and Human Services and a Volunteer of the Year award from the Gift of Life.

"I am truly honored and excited that I was appointed to the advisory committee. It is a very special team, and one I will serve proudly," Duncan said. "As a heart transplant recipient, I am very grateful and blessed that I only had to wait four days for a new heart. I will continue to give back to the community by spreading awareness of organ donation and what a truly wonderful gift it is."



HEIDI HERNANDEZ

Heidi Hernandez was appointed to the committee on February 16, 2011, representing an organ procurement organization, the Midwest Transplant Network (MTN). Hernandez has been a registered nurse for the past 19 years. She currently serves as the director of hospital services and community education at MTN, where she has been committed to working toward its life-saving mission since 2009.

"As a GODAC member, I look forward to advocating for organ and tissue donation and transplantation and working to increase the number of actionable designated donors, as more than 1,300 fellow Missourians await life-saving transplants," Hernandez said.

"I am humbled to serve and fulfill my duties on this committee to increase awareness for the importance of organ donation. I resolve to be committed to GODAC's efforts and support the DHSS in maintaining an effective and efficient donor registry in the state of Missouri."

It's critical for us to encourage everyone we know to join the first-person authorization Missouri Organ and Tissue Donor Registry. The lives of our fellow Missourians on the transplant waiting list depend on it."

— Jan Finn, Organ Donation
Advisory Committee Member



JOAN KEISER

Joan Keiser was appointed to the committee on February 3, 2011 as a hospital representative. Keiser has served as a chaplain at St. John's Mercy Hospital in Springfield in the neuro-trauma intensive care unit for 15 years.

"I have been privileged to journey with family members who honor their loved one's wishes to be an organ and tissue donor," Keiser said. "I have witnessed the peace that families experience in knowing that their loved one has saved or enhanced the lives of others."

Keiser also participates in Donor Sabbath. "Donor Sabbath is an opportunity to gather with donor and recipient families and observe the healing that has taken place," Kaiser said. "It is a time of gratitude, celebration and remembering those who gave such a beautiful gift that has made life better for another sojourner."



HARRY K. RATLIFF

"I have a passion for organ/tissue donation, and I feel very blessed to serve on the Governor's Organ Donation Advisory Committee whose focus is educating the public and enabling donor families and recipients to tell their story," Keiser said.

Harry K. Ratliff was appointed to the committee on January 26, 2011 as a member of a recipient family. Ratliff is a vice president and wealth management advisor with a major financial advisory firm in the St. Louis area.

As a family member of an organ recipient, Ratliff understands how vital transplants are.

"It is a real honor to serve on the Governor's Organ Donation Advisory Committee, and I am committed to educating citizens regarding organ and tissue transplants," Ratliff said. "This appointment offers me an opportunity to express my gratitude to the donor family by encouraging others to carry out the noble act of organ donation."



DEBRA SIMAITIS

Debra Simaitis was appointed to the committee on January 26, 2011 as a member of a donor family. Ten years ago, Simaitis became a "donor mom" when her daughter, Laura, was fatally injured in a motor vehicle accident.

Simaitis has served as a volunteer and spokesperson for organ donation organizations and currently is an ambassador for Midwest Transplant Network. She also volunteers as secretary for the Lakeview Heights Fire Protection District. Her daughter's story has been featured on the radio and in newspapers, pamphlets and brochures.

"Laura saved or vastly improved the lives of 103 people through organ and tissue donations," Simaitis said. "I am proud to carry on her legacy."

Governor's Organ Donation Advisory Committee

Donor or Recipient Family Representatives

Debbie Simaitis, donor family
Harry K. Ratliff, recipient family
Phil Duncan, heart recipient
Peter Nicastro, double lung and kidney recipient

Hospital Representative

Joan Keiser, Chaplain, St. John's Mercy Hospital

Procurement Agency Representatives

Jan Finn, Midwest Transplant Network
Heidi Hernandez, Midwest Transplant Network
Ronald Walkenbach, Ph.D., Heartland Lions
Eye Banks and cornea recipient
Vacancy

Department of Health and Senior Services Representative

Virginia Beatty, Organ and Tissue Donor Program

2011 COMMITTEE REPORT

The Governor's Organ Donation Advisory Committee and its members spent the year collectively and individually building awareness about organ, tissue and eye donation in all parts of the state. Throughout the year, members wrote letters, sent emails, and made phone calls and personal contacts to spread knowledge and reduce misconceptions about organ and tissue donation.

The committee met three times, in September 2010, November 2010, and May 2011, to review the status of the Organ and Tissue Donor Program, the registry, and the budget balance of the Organ Donor Program Fund. In addition to the regular meetings, a team of students from the Truman School of Public Affairs at the University of Missouri agreed to review the activities of the committee and the program. Three students spent the spring semester speaking to committee members and stakeholders and researching how Missouri's program compared to those in other states. Their findings, largely supportive of the program's design and direction, offered some additional recommendations that were presented at the May meeting.

Committee members also attended and worked countless donation events. Many of the functions took place during National Donate Life Month, observed in April every year. On April 6, 2011, committee members gathered at the Missouri State Capitol with our donation partners. The group was introduced on the floor of the Missouri House and spent the day educating members of the General Assembly and staff about the great need for organ and tissue donation. In order to bring as many people as possible into the discussion, ice cream from Central Dairy was served in the Capitol Rotunda. A week later, committee members returned to Jefferson City to meet with Gov. Jay Nixon as he signed the proclamation declaring April to be Organ and Tissue Donation Awareness Month in Missouri.

Members also supported other events in April. Former chairperson Ron Walkenbach staffed the donation sign-up booth at the Missouri Lions State Convention in St. Charles and attended the Donate Life Rally held at the University of Missouri. KOMU-TV reporter Jessica Smith interviewed new committee member Debra Simaitis at the Donate Life Celebration, and a Rose Dedication Service was held at Columbia's University Hospital.

Awareness activities are not limited to April, however. August 1, 2011, is National Minority Awareness Day, and former committee member Lisa Atkins was a guest on the "Radio Friends with Paul Pepper" show on Columbia – Jefferson City radio station KBIA-91.3 FM. New committee member Rev. Joan Kaiser, who is a hospital chaplain at St. John's Mercy Hospital in Springfield represented the hospital as part of a multi-faith Donor Sabbath service on May 21, 2011. She spoke to more than 100 people at Campbell United Methodist Church about the life-saving and affirming gift of organ, tissue and eye donors.

"Sometimes our light goes out but is blown into flame by another being. Each of us owes thanks to those who have rekindled this light."

- Albert Schweitzer
Philosopher and Physician

2011 EDUCATIONAL INITIATIVES

Department of Health and Senior Services

The Department of Health and Senior Services (DHSS) staff continues to work on educational initiatives to promote organ donation as well as work with partners in a coordinated manner to share responsibilities and to communicate the same message. Some of the educational initiatives in which DHSS participated in fiscal year 2011 include:

- Department Director Margaret Donnelly participated in a radio interview about her family's personal experience with living organ donation, attended the April 14, 2011 governor's proclamation signing and has been working with the Department of Revenue Director to further efforts in registering individuals as organ and tissue donors at Missouri's local contract fee offices.
- Staff included several articles in the department's Friday Facts, a weekly electronic newsletter for local public health agencies.
- Staff updated the www.MissouriOrganDonor.com website and participated in the Donor Awareness Day at the state's capitol during April 2011, Donate Life Month.
- Information about organ and tissue donation was provided by program staff at a booth for the Missouri State Employees Charitable Campaign.
- Resources about organ and tissue donation for elementary and secondary school educators were added to the www.MissouriOrganDonor.com website.
- A newsletter to local contract license offices was continued on a semi-annual basis, highlighting registry enrollment and transaction ratios at the local offices, information on how to obtain resources to educate staff and patrons about organ and tissue donation, and information to assist local offices in performing their duty to ask patrons about the organ and tissue donor registry.
- Staff participated in Team Missouri meetings and assisted with drafting a 2011 strategic plan for the Show Me Your Heart Campaign. Team Missouri is a statewide group working on a national collaborative to educate the public about making an informed decision about organ and tissue donation.
- The Missouri Hospital Association (MHA) and the DHSS continued to work together to share information through MHA emails.
- Staff provided information and registry enrollment opportunities at a DHSS blood drive, a meeting of new local public health agency administrators and the Callaway County Community Health Fair.
- Staff gave presentations about organ and tissue donation to two local civic groups, the Jefferson City Breakfast Rotary Club and the Jefferson City Cosmopolitan Group.
- Staff participated in discussions with various groups at the University of Missouri-Columbia campus about upcoming educational and registry drive opportunities for staff and students.



Department of Revenue

The Missouri Department of Revenue (DOR) sent out four articles during state fiscal year 2011 to local contract license offices throughout the state regarding the Organ and Tissue Donor Program. Article topics included:

- August 27, 2010 – The obligations of medical staff at the time of donation for Missouri residents who have the organ donor indicator on their driver's license.
- September 24, 2010 – The availability of free "Show Me Your Heart" posters to license offices to promote the importance of organ and tissue donation and to encourage Missourians to sign up for the registry.
- May 20, 2011 – DOR's formation of an Organ Donation Team, which works in coordination with DHSS to increase awareness about organ and tissue donation. Missouri law requires license offices to ask applicants if they want to be included in the Missouri Organ and Tissue Donor Registry and if they want to donate \$1 to the Organ Donor Program Fund. The team will gather input from license offices about ways to enhance customer participation.
- May 27, 2011 – The top three license offices achieving the highest percentages of organ donor registry enrollment so far during the year: Des Peres, 57 percent; Liberty, 56 percent; and Lee's Summit, 55 percent. The percentage for all license offices can be seen on the Missouri Organ Donor website at www.MissouriOrganDonor.com. Click on "Reports" and "Enrollment Percentages Ranked by Office Average Enrollment."

Heartland Lions Eye Banks

In addition to participating in health fairs and donation awareness walks throughout the year, the Heartland Lions Eye Banks (HLEB) places a special emphasis on educational initiatives during National Eye Donor Month in March. During the month, hospital services staff sponsors Hospital Appreciation Days at medical centers throughout the state. These events celebrate the achievements of hospital staff in the donation process and serve as donor drives, allowing hospital employees and visitors to register as eye, organ and tissue donors. Hospital staff coordinators also provide educational seminars to nursing staff in conjunction with these events.

The Eye Banks public relations team plays a key role in education during National Eye Donor Month as well. Staff members work closely with media outlets in each of the organization's branch cities to develop stories promoting eye donation. The most successful effort concluded with TV and newspaper reports in Kansas City, Mo. about Garry and Larry Hocker, twin cornea recipients who received their transplants on the same day from the same donor.

For more information on promoting eye donation during National Eye Donor Month, contact the HLEB public relations department at 1-800-283-1982 or pr@hleeb.org.

Mid-America Transplant Services

Mid-America Transplant Services (MTS) engaged nearly 6,000 students during the 2010-2011 school year through its on-site student education program designed to teach high school students about the organ and tissue donation process. The program provides free bus transportation to the MTS facility for participating schools in St. Louis, St. Louis County and surrounding areas.

During the on-site, highly interactive presentation, students are given information about organs and tissues that can be donated, who is eligible for donation and how organs are allocated. Students also discuss the role of MTS, the need for organ and tissue donation and how to sign up to be an organ and tissue donor. The most important topic addressed is students talking with their family about organ and tissue donation and the wishes of each family member.

The presentation concludes with a tour of the MTS facility, including the operating room, intensive care unit, eye bank, communications center and AlloSource, a partner with MTS that responsibly develops, processes and distributes live-saving and life-enhancing human tissue.

A new 2011-2012 education program, "Be a Part of It," is a teacher resource guide, which includes a 30-page interactive PDF file with information, videos and online resources to further engage students.

Contact T'Shon Northern, MTS education coordinator, at 314-735-8456 for more information.

Midwest Transplant Network

- Heidi Hernandez, a member of the Governor's Organ Donation Advisory Committee, leads the Midwest Transplant Network's (MTN), Donation and Transplantation Action Council, which focuses on developing and implementing strategies to improve donation processes and outcomes. As director of hospital services and community education, Hernandez championed two key education events. A clergy symposium provided education and resources about organ and tissue donation and transplantation to area clergy, hospital chaplains and faith leaders. Second, a collaborative education event was held for MTN hospital staff, nurses, physicians and other partners in donation and transplantation.
- MTN hosted its annual donor family picnic August 27. The event is a family-friendly outing that brings together hundreds of people – including donor families, recipients and MTN employees – to honor and celebrate those who have given the gift of life.
- Each year a gift of life memorial service to honor its organ and tissue donor heroes is held and coincides with National Donor Sabbath.
- The Work Place Partners program has continued to be very successful. MTN added 17 additional work-place partners this past year.
- MTN added a full time staff person, Sarah Jane Dolezal, who will be working with all the department of motor vehicle and treasurer's offices in the entire state of Kansas and the western two-thirds of Missouri.
- Staff and volunteers reached more than 3,000 students through educational programs conducted at nursing schools, licensed practical nursing programs, high schools and middle schools.
- MTN teamed up with Heartland Lions Eye Banks, University of Kansas Renal Transplant Program and DaVita to offer free screenings at a number of health fairs throughout the year.
- Staff participated in a successful day at the state capital and a proclamation signing for Organ, Tissue and Cornea Donation.

Missouri Kidney Program

The Missouri Kidney Program (MoKP) provides free patient and family education classes for patients who are nearing kidney failure. The purpose of these classes is to offer strategies to prevent or delay kidney failure progression, dietary tips, and information about treatment options, including transplantation. The weekend classes are located throughout the state. Future dates and location of these classes can be found at: <https://mokp.missouri.edu/public/classes.asp>.

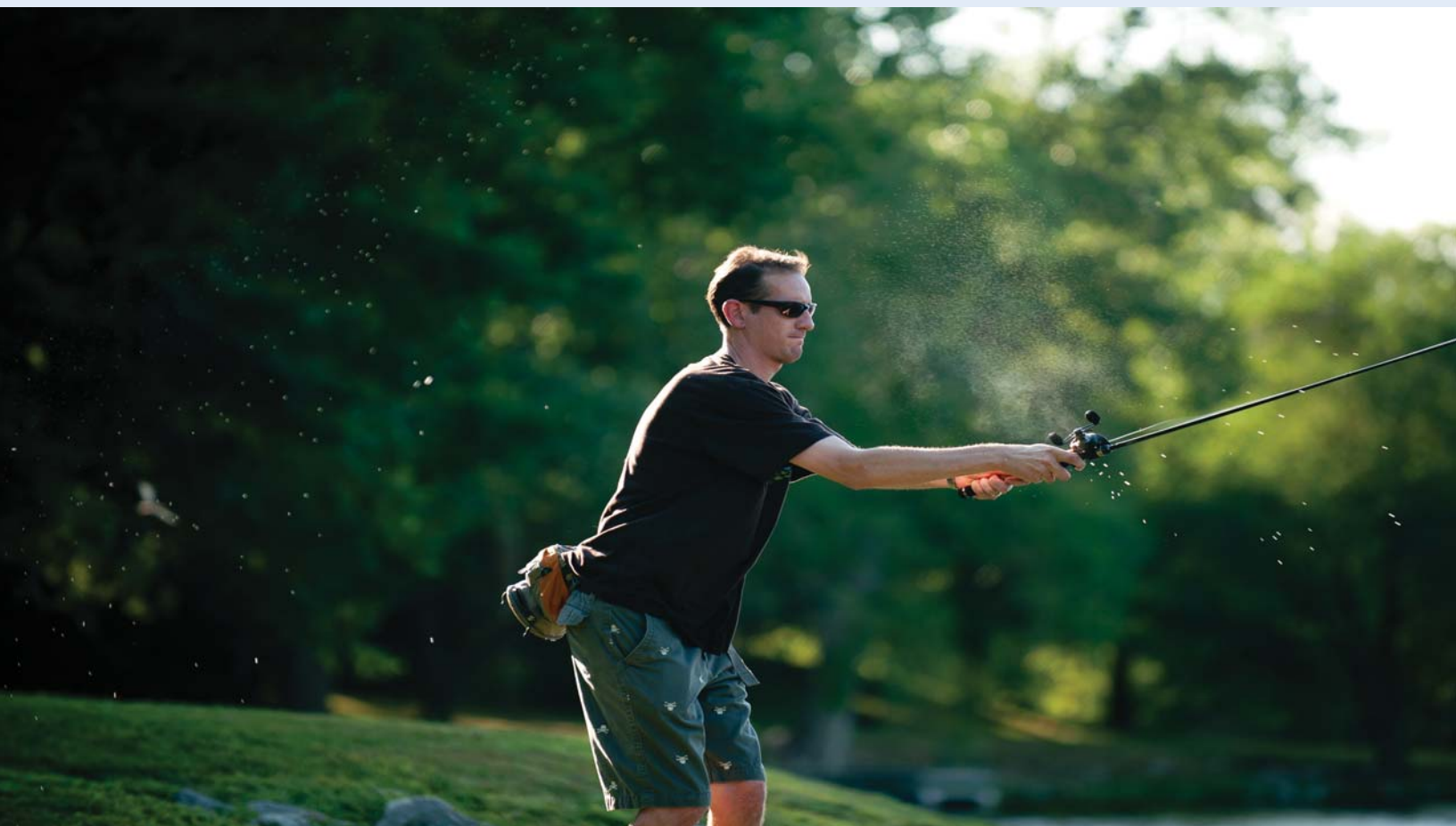
For the past three years, MoKP has partnered with Dr. Amy Waterman of Washington University, St. Louis. She was awarded a Health Resources and Services Administration (HRSA) grant to educate Missourians about the benefits of pre-emptive kidney transplantation. A pre-emptive transplant is a kidney transplant performed before dialysis begins. This provides the best medical outcome for the patient. A pre-emptive transplant requires patients to be aware they have kidney disease early, informed about the opportunity for a transplant, and start the transplant evaluation process as soon as possible. The grant provided funding to hold 14 extra patient education classes specifically targeting the minority and rural population. Study results and article are pending.

MoKP also assists needy Missourians who are kidney transplant and dialysis patients with their medication costs. Kidney patients on average can take 20 different medications a day. Offering assistance with medications supports the health and well-being of patients and decreases their financial burden.

For more information about the MoKP, call 1-800-733-7345 or visit: <http://som.missouri.edu/mokp/>.

An organ donor helped Chris Meyer regain
his vision and his passion for fly-fishing.

THE GIFT OF SIGHT





Chris Meyer

**by Annie Kuhl
Heartland Lions Eye Banks**

Tying a fly for fishing can be difficult enough for someone with 20/20 vision. But for a person suffering from a blinding eye condition, the challenge can be nearly impossible.

For Chris Meyer, the deterioration of his eyesight was stealing away the joy of a sport he loved. For years, the Kansas City resident suffered from eye problems that left his vision compromised.

"Everything was a big haze," he explained. "I would see ghost images, like four or five visions of the same chair. There were a lot of halos, a lot of flares, rings around taillights. The haze filled up my whole vision, making it hard to do anything."

In his early 20s, Chris was diagnosed with kerataconus, a disorder that causes the cornea to become distorted. Chris was fitted with hard contacts to correct his eyesight, but as he grew older, the contacts became more cumbersome while his vision continued to deteriorate. Kerataconus affected his job in information technology, limited his ability to drive, and worst of all, affected his passion for fly-fishing.

In 2004, Chris underwent a cornea transplant on his left eye under the care of Dr. Joseph Tauber. Although the first three weeks of his recovery were highly uncomfortable, Chris now has 20/20 vision when he wears a soft contact lens.

"Everyone wonders – how do you do that? You actually got your eyeball cut open?" Chris said. "I think one of the reasons people don't get the cornea transplants they need is because it's a scary thought, but it's so worth it in the long run. There's nothing I wouldn't have done to get my vision back."

The first cornea transplant went so well that Chris underwent his second in 2009. "Although my vision's not back 100 percent, it's amazing I have 20/40 vision even without my contact in. I'm not there yet, but I'm better than I was."

While Chris has been blessed with better eyesight, the journey has been bittersweet. Because of his condition, Chris' donors had to be younger than he was and the corneas less than 72 hours old.

"It's such a double-edged sword. What's good for somebody like me meant something bad had to happen to someone else. The hardest thing is knowing what another family was going through," Chris said.

Today, thanks to the gift of his donor families, the talent of Dr. Tauber, and the support of Chris' optometrist, Dr. Jill Smith, Chris is back on the water and fishing.

2011 VOLUNTEERS

Bracelet helps mom deliver message

by Justin Phelps, Mid-America Transplant Services

June Laschober proudly wears a green Donate Life bracelet in memory of her son, Scott. She hopes the bracelet she wears every day will spark a conversation with someone who may not know about organ, tissue and eye donation.

“I became very passionate about organ and tissue donation. I wanted to tell people about it so they would be aware and become donors.”

– June Laschober

June is always looking for opportunities to spread awareness about organ, tissue and eye donation – even to her own doctor.

In 2005, Scott – the middle of three sons born to June and her husband Bob – died in a car accident at age 22 and donated his heart, liver, kidneys, bone and tissue.

“At 6’2”, Scott was like a lovable teddy bear,” June said. “He was such a big kid, every time he walked up the stairs, the dishes in the cabinets across the kitchen rattled.”

“I started wearing my green bracelet to remember my son,” June said. “After he was an organ donor, I became very passionate about organ and tissue donation. I wanted to tell people about it so they would be aware and become donors.”

Since early 2010, June has volunteered at Mid-America Transplant Services (MTS), helping with a variety of clerical jobs involving reports, data entry and preparing mailings. She also serves as a public speaker and a grief companion for donor families.

“When we talk about the ‘human spirit’ that comes to donor families through the gift of donation, June is a perfect example,” said Merry Smith, program manager at the Center for Life. “She received comfort and encouragement through Scott’s donation and now wants to give back to help others have the same experience.”

Shortly after starting with MTS, June’s life was once again impacted by organ donation. She was injured in a car accident and eventually required surgery that involved removing a disc in her back and using donor tissue to fuse the vertebra.

“When the spinal surgeon asked me if I had any problems with tissue donation,” June said. “I proudly held up my wrist with the green bracelet and said, ‘I fully support organ and tissue donation.’”

June Laschober



2011 VOLUNTEERS

Letters promote healing and hope

by Anne Kuhl, Heartland Lions Eye Banks

For many families who have lost a loved one, organ, eye and tissue donation gives them a sense of hope. And when families hear from those who received the donation, it's particularly rewarding.

In 2010, Carol Culley lost her 30-year-old son, Mark. Unbeknownst to the family, Mark had made the pledge to become an eye donor through Missouri's first-person consent registry – a move that didn't surprise Carol.

"Mark was absolutely the most loving person in our family," she said. "He cared very much about his family – about everybody. He didn't know a stranger. Mark was never judgmental, gave everybody a fair chance, and always tried to help the underdog."

As Carol and her family moved through the grieving process, they received a letter from Heartland Lions Eye Banks informing them that Mark's corneas had been provided to two recipients in California. Carol wrote the recipients, introducing them to her son. She soon received letters back from both individuals. One recipient in particular struck a chord with Carol, and the two began corresponding frequently.

The Eye Banks' correspondence program has not only helped in the healing process for Mark's immediate family, but for his church family as well. Carol read the letters she received to the church members, helping them to find hope in a desperate situation and to follow Mark's lead by pledging to become eye, organ and tissue donors.

In April 2011, Carol shared her story with the Eye Banks staff at the organization's annual skills day. She stressed how the correspondence program made a difference for her family and how other families could benefit from the service. Since then, she has volunteered to speak on behalf of the Eye Banks at events in mid-Missouri to encourage residents to join the state's first-person consent registry.



Carol Culley and her son Mark

Carol stressed how the correspondence program made a difference for her family and how other families could benefit from the service.

2011 VOLUNTEERS

Family celebrates son's legacy

by Ray Gabel, Midwest Transplant Network



Donna Lawrence

"He was the type of kid who soaked up life. He had constant wonder in his eyes and a contagious smile. He always had a kind word and never met a stranger. He would do anything for anybody and would always ask how you were doing or how your day was going," Donna Lawrence said about her son, Dakota.

When Dakota was 8 years old, Donna and her family were faced with making a decision about donating his organs.

"When we were approached about donating, there was no hesitation. We knew Dakota would want it that way. If he could save someone's life, he would do it in an instant," Donna said. "He told me that he wanted to be a doctor so that he could save little kids' lives and make them better. He never got the chance to be a doctor but he has saved lives."

In honor of Dakota, the Lawrence family co-sponsors the Annual Dakota Lawrence Memorial Volleyball Tournament in St. Joseph. For the past seven years, the two-day event has drawn large crowds to celebrate Dakota's legacy and

increase organ donor awareness. Through their volunteer efforts, the Lawrence family has adopted a slogan that reflects Dakota's legacy: "Give Life – Dakota did."

"It's comforting to us to know that there are three people alive because of Dakota. In a sense, Dakota is living on. It's ironic that the person who received Dakota's heart is an 8-year-old boy and a twin – just like Dakota," Donna said. "We keep each recipient in our hearts and prayers and hope they are doing well. It would be wonderful to meet them someday."

Donna has volunteered her time to share her son's story at local hospitals and gives countless hours to the volleyball tournament. In 2008, the Lawrence family was chosen to represent donor families from the Midwest Transplant Network at the National Kidney Foundation's U.S. Transplant Games in Pittsburgh, Pa.

It's comforting to us to know that there are three people alive because of Dakota. In a sense, Dakota is living on."

– Donna Lawrence

2011 VOLUNTEERS

Transplant takes life in new direction

by Keith Anderson, Gift of Life

Amy Honeycutt is a 27-year-old nursing student at the University of Missouri - Kansas City with a life full of friends, family, fun and a willingness to volunteer.

In the spring of 2011, an adverse reaction to a routine medicine Amy received abruptly took her life in a different direction. Her liver stopped functioning within days, and she needed a liver transplant. At that point, she became too ill to make her own decisions.

"I will forever be grateful to the friends and family who surrounded me at that time," she said.

Amy made sure everyone understood that the generosity and decision of one donor and the donor's family is the reason she is alive today.

Because the Kansas City area has a high percentage of registered organ donors, her wait for the gift of life was only 48 hours. She received her new liver at the University of Kansas Hospital.

Seven weeks later, in August 2011, she embraced the new direction her life had taken and decided to volunteer for Gift of Life in Kansas City. She hosted a pool party and raffle for friends and family in North Kansas City. Amy made sure everyone understood that the generosity and decision of one donor and the donor's family was the reason she is alive today.

Amy also participated in training to become a classroom speaker for the Life Savers program, led by Gift of Life. Last year, the Life Savers program was delivered at no charge to 80 area high schools, reaching more than 20,000 individuals.

Through her efforts Amy has raised the bar for volunteerism in Kansas City and is leading others on her path to promote the importance of organ donation.

Amy Honeycutt



2011



Donate Life Missouri ▶ Twitter



DonateLifeMO

Friday's Fact: Very few medical conditions automatically disqualify you from becoming an organ and tissue donor.

PROMOTING DONATION THROUGH SOCIAL MEDIA

With the rapid growth of social media, the Missouri Organ and Tissue Donor Program is using these new channels to expand communication with the public about the importance of organ and tissue donation.

The Department of Health and Senior Services (DHSS) produced a YouTube video during fiscal year 2011 featuring a story about Richard Black, the now-retired police chief of Glendale, who received a living kidney donation from his daughter, Katie Horton. Both are from the St. Louis area. Their story can be viewed at http://www.youtube.com/watch?v=z_eF8otqNcg.

DHSS's Organ and Tissue Donor Program is part of a state-wide team, Donate Life Missouri – also referred to as Team Missouri, which is using social media in its public awareness efforts. Individuals can learn about organ and tissue donation, share their thoughts and personal experiences, Tweet, record their decision about organ donation, and more – all from one Facebook page.

Team Missouri is part of a national collaborative to educate the public about making an informed decision about organ and tissue donation and recording that decision in Missouri's registry.

Join the Donate Life Missouri Facebook page at: <http://www.facebook.com/DonateLifeMO>.

2011 FINANCIAL SUMMARY

Registry funding

Funding for the Organ and Tissue Donor Program during fiscal year 2011 came from local driver license and motor vehicle offices that collect the \$1 donation, specialty plate contributions (\$25 or \$50), contributions made in honor of a loved one, and the Missouri State Employee Charitable Campaign. After passage of HB151 in 2011, individuals will also have the option of donating by using a check-off box on their income tax return in 2012.

Figure 1 shows yearly contributions to the Organ and Tissue Donor Program. The average contribution for the most recent five-year fiscal cycle was \$140,587, down slightly from the previous five-year fiscal cycle (fiscal years 2002 through 2006) of \$180,713. Fiscal years 2010 and 2011 had yearly contributions above the current five-year average.

Decreasing expenses

As predicted, expenses for state fiscal year 2011 dropped significantly. Registry operations for fiscal year 2011 are at a maintenance level. Information technology (IT) expenditures, while minimal, were incorporated into personnel services, staff benefits and administrative overhead.

Program supply expenses were up slightly. The increased cost of printing supplies resulted in the educational initiatives line item being slightly higher than fiscal year 2010.

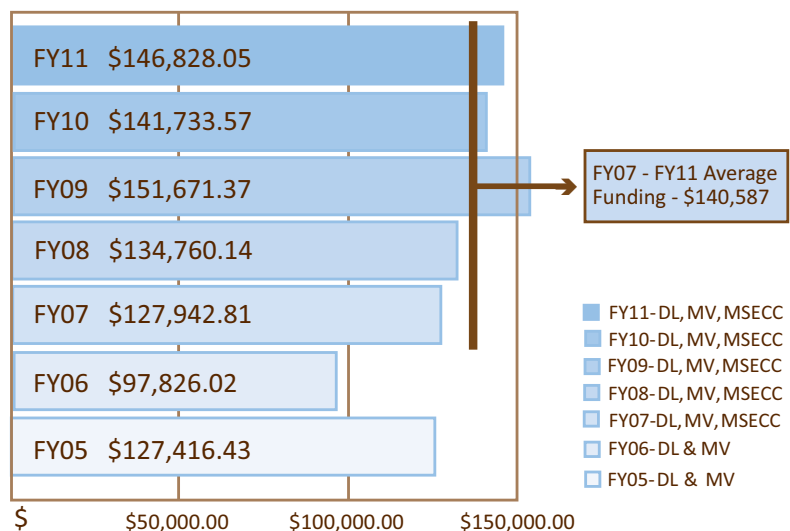
DHSS staff and the Governor's Organ Donation Advisory Committee continue to closely monitor revenue and expenses.

More information about registry and program funding can be found at www.MissouriOrganDonor.com, and click on "Make a Contribution."

Figure 1: Statement of activities

Fiscal years (FY) ending June 30, 2010 and June 30, 2011		
Fund Revenues	FY10	FY11
Contributions/Interest		
- Department of Revenue contributions	138,682	142,949
- Direct contributions/specialty plate	1,500	3,031
- State Employee Charitable Campaign	1,551.66	848
- Investment interest	0	0
Total Revenue	\$141,734	\$146,828
Fund Expenses		
Registry		
- Participation	722	237
- Operations	394,939	23,702
- GODAC Meeting	0	165
- Adjustment-Prior IT Balance	0	0
- IT Expenditures	16,243	0
- Educational initiatives/annual report	1,669	1,705
Personnel services	67,673	70,248
Staff benefits (fringe benefits)	31,663	35,855
Administrative overhead		
- Indirect costs	22,648	24,191
- Network allocation	4,188	3,203
- Program supplies and expenses	476	785
Total Expenses	\$540,221	\$160,091
Beginning Fund Cash Balance	474,282	80,931
Change in Net Assets		
- Income	141,734	146,828
- Network Adjustment	1,027	-772
- Indirect Adjustment	4,110	-8,132
- Expenditures	-540,221	-160,091
Ending Fund Cash Balance	\$80,931	\$58,764

Figure 2: Contribution history, by fiscal year



2011 DONATION & TRANSPLANTATION

Missouri needs to continue to educate the public about organ and tissue donation to not only save lives, but also to close the gap between the need for organs and the number of organs available for transplantation; dispel myths about organ donation and transplantation; and reduce the risk of high blood pressure and diabetes – two of the most common conditions that create a need for organ transplantation.

Figures 1 through 5 show a variety of data related to organ donation and transplantation in Missouri, including the gap between the need for and donation of organs.

There is also a need for Missouri programs that focus on chronic disease prevention and control for patients and professionals – such as third-party payers, physicians, nutritionists, etc. – to work on reducing the need for transplants through chronic disease management.

"Since diabetes and high blood pressure are the top two causes of end-stage renal disease, any effort toward prevention would reduce the need for the expensive, life-sustaining treatment of dialysis or kidney transplantation," said Leanne Peace, director of the Missouri Kidney Program.

Missouri residents can reduce their risk for developing high blood pressure and diabetes or control these conditions by taking steps to live a healthy life by exercising at recommended levels, eating a diet rich in fruits and vegetables, and limiting sodium intake.

Figure 1: Registrants ever waiting by age, by fiscal year

Age	FY08	FY09	FY10	FY11
<1	20	24	25	14
1-5	27	20	22	20
6-10	13	15	13	27
11-17	48	42	31	43
18-34	340	324	328	298
35-49	655	644	614	601
50-64	903	891	899	962
65+	212	260	319	317
Total	2,218	2,220	2,251	2,282

Note: Number ever waiting for a transplant by age, by fiscal year where the candidates home state is Missouri. Candidate age is at the time of listing. Registrations may be counted in multiple rows for "Date Ever Listed."

Figure 2: Deceased donors recovered by age, by fiscal year

Age	FY08	FY09	FY10	FY11
<1	3	2	1	5
1-5	8	4	11	7
6-10	4	1	4	1
11-17	18	15	10	10
18-34	59	60	59	72
35-49	57	50	53	41
50-64	47	54	41	73
65+	25	30	22	18
Total	221	216	201	227

Note: Number of deceased donors recovered with Missouri as home state by fiscal year (FY).

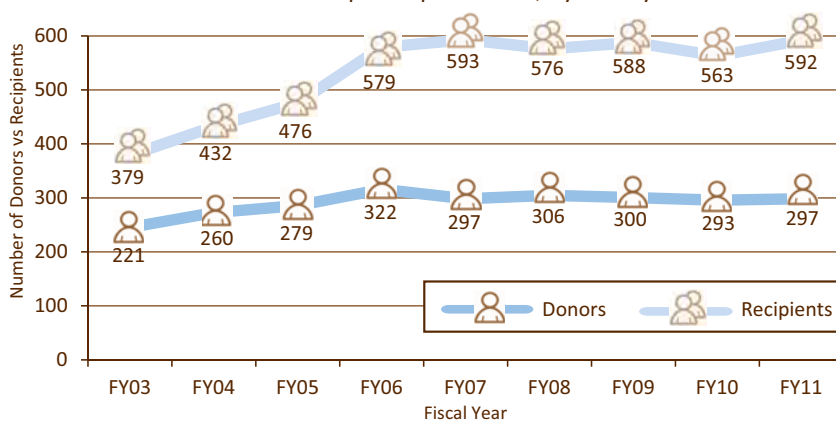
The actual number of organ donors in Missouri will continue to fluctuate from year to year, while the gap between those donating organs and those needing a transplant remains an issue.

Kidney and liver transplants are the most often performed transplants followed by heart, lung and kidney-pancreas transplants.

The United Network of Organ Sharing (UNOS) provides the numbers in the figures to the Department of Health and Senior Services (DHSS) through special data requests. Data are subject to change due to future data submission or correction.

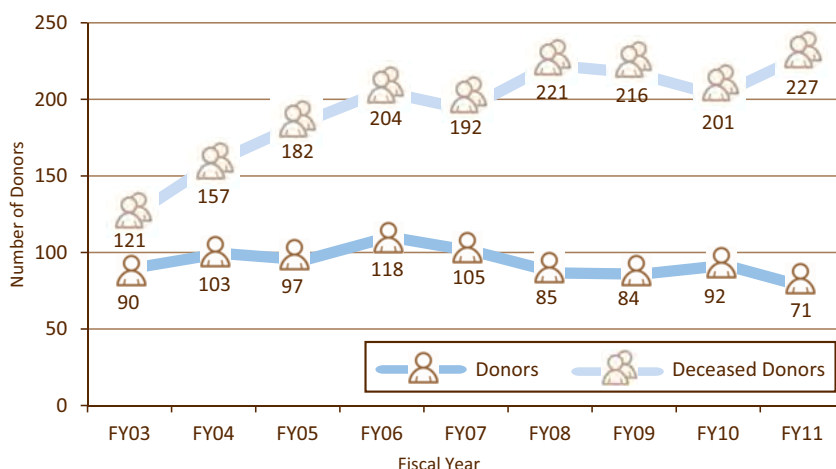
Several factors influence the numbers in the graphs including: individuals transplanted, too sick to be transplanted, non-compliant with transplant center requirements, passed away while waiting and new individuals being added to the list.

Figure 3: Missouri donors vs. transplants performed, by fiscal year



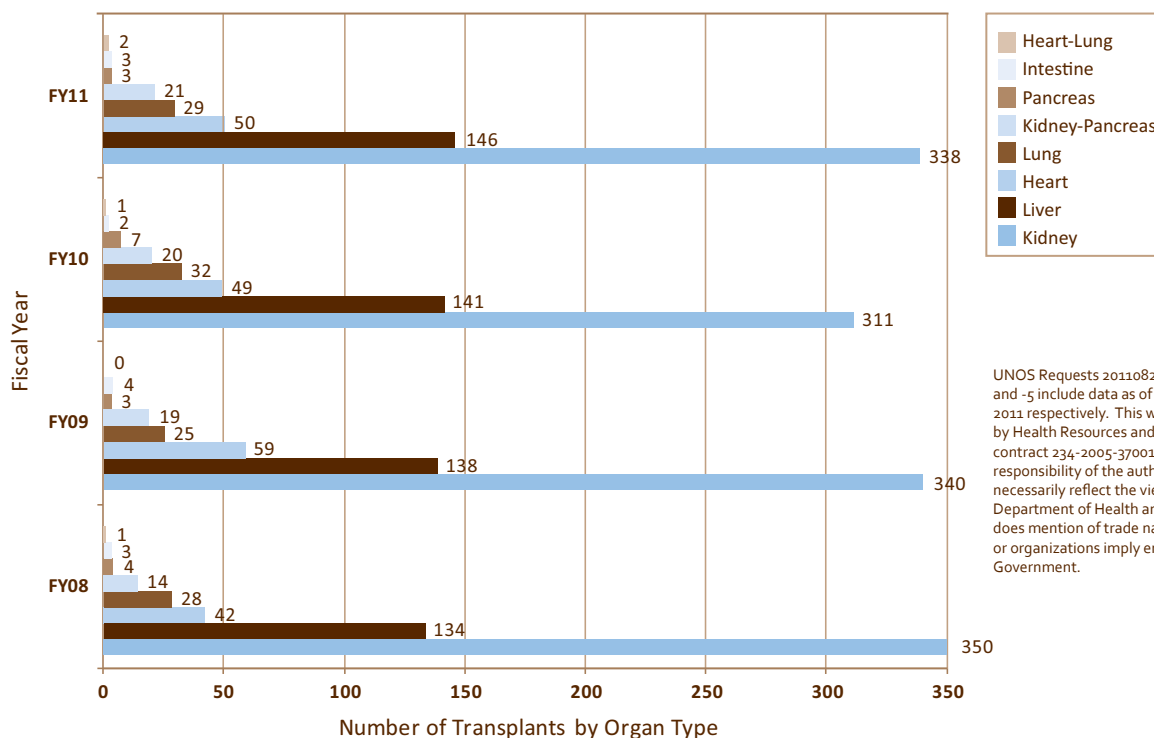
Note: Number of donors recovered where donor home state was Missouri vs. number of transplants performed where recipient home state was Missouri.

Figure 4: Missouri donors, by fiscal year



Note: Number of deceased donors recovered with Missouri as home state by fiscal year (FY).

Figure 5: Transplants performed, by organ type



UNOS Requests 20110825-2 thru -4 and 20110919-4 and -5 include data as of Sept. 2, 2011 and Sept. 23, 2011 respectively. This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Government.

2011 MISSOURI DONOR DESIGNATION REPORT CARD

The Donor Designation Collaborative (DDC), launched in October 2006, has evolved from a stand-alone initiative to an integrated state-by-state operational strategy. State teams share best practices and create and maintain high-functioning state donor registries. Together, the national and state teams work to increase the number of designated donors and the donor designation rate in the United States. Goals are listed in Table 1.

Table 1: National goals

100 Million Designated Donors
50% Donor Designation Rate

Source: National Donor Designation Report Card, April 2011

State teams began submitting data quarterly in 2008 to the national team that conducts analysis and produces the National Donor Designation Report Card every April. In the 2009 report, Missouri had a 33 percent donor designation rate (refer to standards below) and ranked in the top 20 states submitting data. Missouri remained in the top 20 states as indicated in both the 2010 and 2011 reports with a 36.3 percent and 39.5 percent designation rate

respectively. The Donate Life Missouri team will continue to work together to increase awareness about organ and tissue donation so that Missouri's residents can make and record an informed decision.

According to the April 2011 National Donor Designation Report Card (www.donatelife.net), the work of all state and national team efforts has resulted in 94.7 million individuals being registered as donors – an increase of 3.5 percent in four years. Efforts also helped facilitate more than 111,000 organ transplants, approximately 160,000 cornea transplants and millions of tissue transplants since 2007. Through collaborative efforts, the percentage of organ donations, tissue donations and eye donations authorized through state donor registries has increased (Table 2).

National and Missouri standards

- Donor Designation Rate, rate at which individuals join the state donor registry as a percentage of all driver licenses and ID cards issued within a specific period of time, meets or exceeds 50 percent. **Missouri – Current Status: 39.5 percent** (National Donor Designation Collaborative Report Card, April 2011 – calendar year 2010 data)
- Actionable Donor Designation (ADD) Population 18 years of age or older meets or exceeds 50 percent share, or approximately half of the adult population. ADD refers to an individual's decision to make an anatomical gift recorded in a searchable donor registry. **Missouri – Current Status: 60 percent-Includes all ages** (National Donor Designation Collaborative Report Card, April 2011 – calendar year 2010 data)
- Percent of recovered designated organ, eye and tissue donors who are registered reaches 40 percent or higher. **Missouri-Current Status: 80 percent** (Missouri Donor Designation Collaborative Quarter 2 Report, April 1 – June 30, 2011)

Table 2: Percent of donors listed on state donor registries

	April 2009	April 2010	April 2011
Organ Donors	25.2%	28.4%	32.8%
Tissue Donors	27.2%	29.6%	37.3%
Eye Donors	32.8%	37.6%	42.2%

Source: Donate Life America, National Donor Designation Report Cards

Missouri partners realize the demand for organs currently out-weighs organ availability and that educational efforts including the Show Me Your Heart Campaign and registry enrollment efforts need to continue. As of June 30, 2011, more than 1,330 Missouri residents were on the organ waiting list.

Table 3: Registry enrollment at the end of the fiscal year

	FY08	FY09	FY10	FY11
Intent	2,417,750	2,040,695	1,886,913	1,649,055
Consent	0	400,650	835,227	1,204,739
Total	2,417,750	2,441,345	2,722,140	2,853,794

Source: Donor Registry System

As Missouri continues its six-year drivers license renewal process, the number of individuals in the intent registry is expected to decline and the numbers in the consent registry to rise (Table 3). It should be noted that registry numbers are also influenced by monthly purging of registry records of individuals who are deceased or who request to be removed.

Program processes nearly 800,000 transactions during fiscal year 2011

The Missouri Department of Health and Senior Services (DHSS) processed nearly 800,000 transactions for the organ donor registry during fiscal year 2011 (Table 4). The transactions either updated existing registry records, added new records, removed individuals who are deceased (Vital Records), or removed individuals from the registry by request. Of the 4,319 paper forms processed, 2,822 were updated records, 425 were new enrollees, and 1,072 were removals from the registry. New enrollees, all methods of enrollment for fiscal year 2011, was 150,006.

Table 4: Registry transactions

	FY10	FY11
Remote Enrollment	0	7
Online Enrollment	2,629	2,639
Paper Forms	2,374	4,319
Department of Revenue	822,387	786,809
Vital Records	12,398	19,122

Registry numbers by age

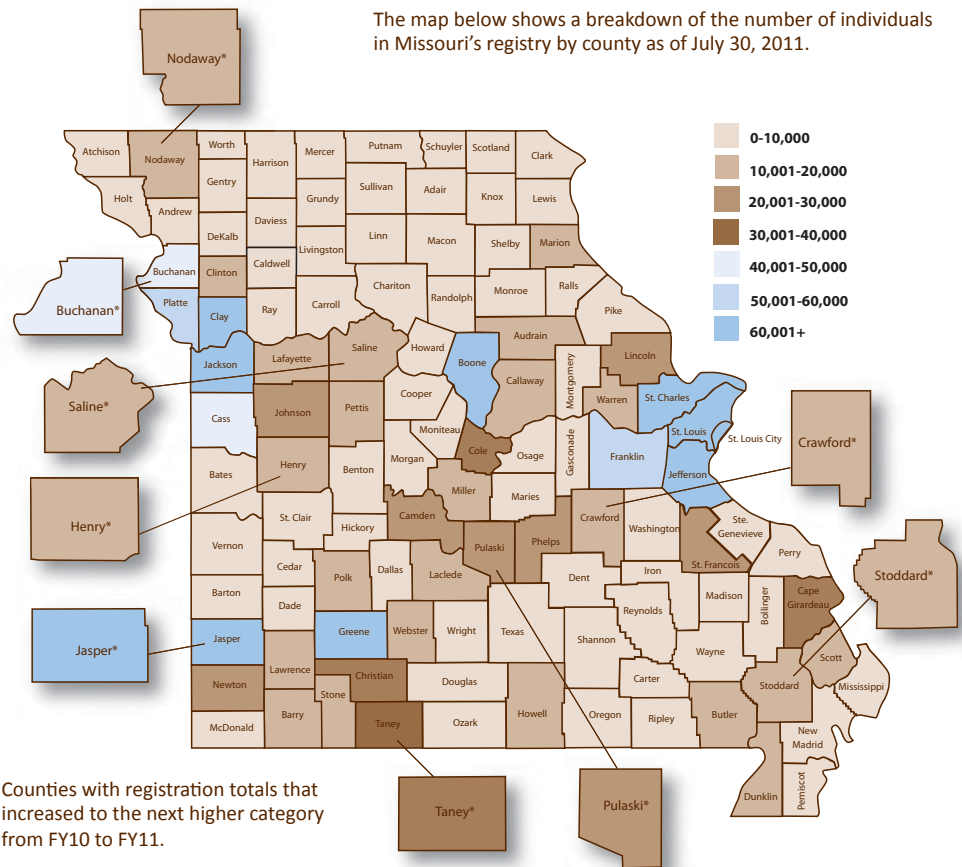
Table 5 provides a breakdown of all registrants at the end of fiscal year 2011. The map illustrates the number of individuals in the registry by county at the close of fiscal year 2011. The registry system automatically adjusts the age category of individuals based on their birth date.

When looking at the total number of registrants by age distribution in fiscal year 2011, there is not much difference between the age categories of 18-24 through 35-44. Collaborative educational efforts by Missouri's partners continue to close the gap between age groups.

Data represent consent and intent records and is a snapshot as of July 2, 2011.

Registry breakdown by county

The map below shows a breakdown of the number of individuals in Missouri's registry by county as of July 30, 2011.



* Counties with registration totals that increased to the next higher category from FY10 to FY11.

Table 5: Total Missouri registrants, by age, as of July 2, 2011

Age Category	Total Registrants End of FY	% of Registrants - All Ages	% of State's Population - All Ages
14 or younger	12,522	0.4%	0.2%
15-17	158,384	5.6%	2.6%
18-24	539,996	18.9%	9.0%
25-34	557,246	19.5%	9.3%
35-44	514,623	18%	8.6%
45-54	497,810	17.5%	8.3%
55-64	336,514	11.8%	5.6%
65 or older	235,444	8.3%	3.9%
Total number of registrants – all ages, end of FY11		2,852,539	47.6%
State population – all ages, U.S. 2010 Census		5,988,927	

2011 LICENSE OFFICES

The Missouri Organ and Tissue Donor Program, the Missouri Department of Revenue and partner organizations are committed to supporting the efforts of the state's local contract license offices to inform Missourians about the Organ and Tissue Donor Registry.

Local contract license offices located throughout Missouri are responsible for 98 percent of all registry enrollments. They also generate revenue for the operation of the registry through contributions made by Missouri residents when renewing their licenses.

The local contract license office registry enrollment average for fiscal year 2011 (July 1, 2010 – June 30, 2011) was 37 percent. The registry enrollment average goal for fiscal year 2012 is set at 40 percent. The office average for contributions to the state organ donor fund for fiscal year 2011 was 6 percent. The average fund contribution goal for fiscal year 2012 is 10 percent.

A number of local contract license offices were successful in reaching registry enrollment and driver/non-driver license fund contribution goals in fiscal year 2011 (July 1, 2010 – June 30, 2011). The top offices were:

License Office	Enrollments
Des Peres.....	56%
Liberty.....	55%
Lee's Summit.....	55%
West County.....	52%
Camden.....	52%
Platte City.....	52%
Nixa.....	52%
Clayton.....	52%
Parkville.....	51%
Harvester.....	51%
Gallatin.....	51%

License Office	Contributions
Lamar.....	32%
Fayette.....	29%
Plattsburg.....	27%
Hartville.....	27%
Harrisonville.....	26%
Parkville.....	22%
Jefferson City.....	22%
Herman.....	18%
Fredericktown.....	18%
Joplin.....	17%
Princeton.....	17%

"The great work done by these local contract license offices sets the standard in registering potential donors and supporting the registry," said Peter Nicastro, chairperson of the Governor's Organ Donation Advisory Committee. "The organ donor registry could not operate effectively without the efforts of the local offices."

Beginning with fiscal year 2012 (July 1, 2011 – June 30, 2012), the Organ and Tissue Donor Program will be presenting quarterly "Awards of Excellence" to local contract license offices with the highest percentage of enrollments and/or fund contributions per driver/non-driver license or motor vehicle transaction. Registry enrollment awards will be given in five categories based on total quarterly transactions. Awards for the highest fund contribution percentage will be presented in two different categories, driver's license and motor vehicle contributions.

Reports for each local contract license office in Missouri are available at www.MissouriOrganDonor.com. Offices needing assistance in training staff about the registry or the fund can contact the Missouri Organ and Tissue Donor Program toll-free at 1-888-497-4564 or organdonor@health.mo.gov.

The great work done by these local contract license offices sets the standard in registering potential donors and supporting the registry."

– Peter Nicastro, Organ Donation
Advisory Committee Chairperson

MISSOURI REGISTRY PARTICIPATION

ADAIR Kirksville32%	DENT Salem35%	MACON Macon30%	SCOTLAND Memphis34%
ANDREW Savannah41%	DOUGLAS Ava34%	MADISON Fredericktown35%	SCOTT Chaffee40%
ATCHISON Rock Port43%	DUNKLIN Kennett33%	MARIES Vienna39%	Sikeston36%
AUDRAIN Mexico37%	Malden24%	MARION Hannibal40%	SHANNON Eminence32%
Vandalia43%	FRANKLIN Pacific46%	Palmyra49%	SHELBY Shelbina41%
BARRY Cassville36%	St. Clair42%	MCDONALD Pineville39%	ST CHARLES Harvester51%
Monett35%	Sullivan40%	MERCER Princeton39%	O'Fallon48%
BARTON Lamar42%	Union43%	MILLER Eldon42%	St. Charles44%
BATES Butler40%	Washington48%	MISSISSIPPI Charlestone33%	Wentzville47%
BENTON Warsaw44%	GASCONADE Hermann44%	MONITEAU California33%	ST CLAIR Osceola39%
BOLLINGER Marble Hill31%	Owensville34%	MONROE Monroe City44%	ST FRANCOIS Bonne Terre35%
BOONE Columbia50%	GENTRY Stanberry45%	Paris18%	Farmington33%
BUCHANAN St. Joseph24%	GREENE Glenstone47%	MONTGOMERY Montgomery City38%	ST LOUIS Affton38%
BUTLER Poplar Bluff32%	Republic49%	MORGAN Versailles37%	Bridgeton36%
CALDWELL Kingston42%	South Fremont49%	NEW MADRID New Madrid23%	Chesterfield50%
CALLAWAY Fulton30%	Springfield38%	NEOSHO Neosho39%	Clayton51%
CAMDEN Camdenton52%	GRUNDY Trenton36%	NODAWAY Maryville50%	Creve Coeur45%
CAPE GIRARDEAU Cape Girardeau44%	HARRISON Bethany36%	OREGON Alton30%	Deer Creek43%
Jackson34%	HENRY Clinton37%	Thayer33%	Des Peres56%
CARROLL Carrollton35%	HICKORY Hermitage38%	OSAGE Linn40%	Ferguson25%
CARTER Van Buren31%	HOLT Mound City48%	OZARK Gainesville40%	Florissant34%
CASS Belton48%	HOWARD Fayette45%	PEMISCOT Caruthersville31%	North County19%
Harrisonville46%	HOWELL Mountain View28%	PERRY Perryville42%	Oakville42%
CEDAR Stockton28%	West Plains35%	PETTIS Sedalia40%	Olivette29%
CHARITON Keytesville32%	Willow Springs37%	PIKE Bowling Green37%	Overland30%
CHRISTIAN Nixa52%	IRON Ironton27%	Louisiana35%	South County42%
Ozark46%	Viburnum32%	PLATTE Parkville51%	West County53%
CLARK Kahoka45%	JACKSON Blue Springs49%	Platte City52%	ST LOUIS CITY AAA St. Louis38%
CLAY Excelsior Springs44%	Grandview39%	POLK Bolivar37%	North Kingshighway12%
Gladstone38%	Independence30%	PULASKI Waynesville47%	South Kingshighway30%
Liberty55%	Kansas City27%	PUTNAM Unionville35%	St. Louis City Hall28%
North Kansas City41%	Lee's Summit55%	RALLS New London37%	STE GENEVIEVE Ste. Genevieve47%
CLINTON Cameron44%	Raytown39%	RANDOLPH Moberly43%	STODDARD Dexter29%
Plattsburg43%	Sugar Creek34%	RAY Richmond40%	STONE Crane34%
COLE Jefferson City47%	JASPER Carthage45%	REYNOLDS Ellington21%	Lakeview/Branson West45%
Jefferson City Mail In35%	Cooper44%	RIPLEY Doniphan24%	SULLIVAN Milan31%
Jefferson City Mini Branch46%	De Soto34%	SALINE Marshall37%	TANEY Branson48%
COOPER Boonville43%	High Ridge43%	SCHUYLER Lancaster40%	Forsyth41%
CRAWFORD Cuba37%	Imperial44%		TEXAS Cabool22%
Steeleville38%	Twin City44%		Houston29%
DADE Greenfield35%	JOHNSON Warrensburg42%		Licking33%
DALLAS Buffalo33%	KNOX Edina37%		VERNON Nevada42%
DAVISS Gallatin44%	LACLEDE Lebanon41%		WARREN Warrenton41%
DEKALB Maysville47%	LAFAYETTE Lexington39%		WASHINGTON Potosi32%
	LAWRENCE Aurora39%		WAYNE Greenville30%
	Mount Vernon46%		WEBSTER Marshfield42%
	LEWIS Monticello43%		WORTH Grant City34%
	LINCOLN Elsberry36%		WRIGHT Hartville25%
	Troy42%		Mountain Grove28%
	LINN Brookfield37%		
	LIVINGSTON Chillicothe42%		

*Registry participation is for July 2010 to June 2011 and is based on percent of total transactions responding "yes" to being placed on the registry. If the fee agent changed during FY11, the percent may be altered.



Organ and Tissue Donor Program

Missouri Department of Health and Senior Services

P.O. Box 570

Jefferson City, MO 65102-0570

573-522-2847 or toll-free 888-497-4564

Alternate forms of this publication for persons with disabilities may be obtained by contacting the Missouri Department of Health and Senior Services at 888-497-4564. Hearing- and speech-impaired citizens can dial 711.

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